

Open Letter in response to inclusion of the Behaviour Response Utilisation Tool (BRUA) in the aged care funding assessment tool.

By Theresa Flavin

The Australian Government has replaced the Aged Care Funding Instrument (ACFI) with the Australian National Aged Care Classification (AN-ACC) funding model from October 2022.¹ The new funding model includes the Behaviour Resource Utilisation Assessment' (BRUA) which was designed to predict capacity for work in school-leavers with disabilities.²

My name is Theresa Flavin. I'm 56 years old living with younger onset dementia. I am a passionate activist and advocate for the human rights and dignity of people living with dementia, and I work closely with a number of organisations including Dementia Australia and Older Persons Advocacy Network in this capacity.

The Australian National Aged Care Classification (ANACC) tool is the new aged care funding instrument and a key component of Australian Government reform. The AN-ACC was developed to measure 'key cost drivers' in residential care and improve the allocation of funding to better meet resident care needs and to sever the influence of funding on care planning. Resident behaviour is one variable which impacts care delivery costs. Accordingly, the AN-ACC includes the 'Behaviour Resource Utilisation Assessment' (BRUA). This assessment is applied to all residents but will be especially relevant to people living with dementia, as up to 90% experience behavioural symptoms or changes.

Conservatively, 53% of people in aged care are living with dementia, so this element of the AN-ACC may significantly impact this vulnerable group. Many older people living in residential age care also live with PTSD and other mental health conditions which may also impact their behaviour.

¹ <https://www.health.gov.au/sites/default/files/documents/2021/02/an-acc-funding-model---an-introduction.pdf>

² <https://pubmed.ncbi.nlm.nih.gov/36330763/>

When I first read the AN-ACC funding tool, I admit I was reading it from the perspective of a potential person being assessed. I was aware that this was a combination of various assessment tools designed to assess funding requirements as opposed to designing person centred care plans. With this in mind, I was still horrified when I came to the final section containing the BRUA.

To give you some context, it may help if I explain where I'm coming from. When I was diagnosed with dementia, my fears were not around losing my memories, my fears were in relation to potential changed behaviours, where my conscious self is no longer connected to my physical body. The so called Behavioural and Psychological Symptoms of Dementia (BPSD) are the most frightening aspect of dementia, for both those of us living with the disease and our families. Throughout the trajectory of my own disease, I have noticed increasing disconnection between my body and my mind. I have also noticed that the way I think has changed. It's almost as though I have changed from a thinking person with feelings, into a feeling person with thoughts.

The combination of these changes have resulted in my broken brain communicating with my body to express my feelings often in unexpected and unwelcome ways. I have no sense of control of these physical actions, they feel at the time more like a reflex than a purposeful action. Let me give you an example:

When I fell off my horse last year, I had some cracked vertebrae. While the paramedic staff were wonderful, in the emergency room I experienced many challenges of sensory overload. It was overwhelming, as while all of my senses work, the little bits of brain that filter the outside stimulation into manageable and understandable messages is a little broken, so it's a bit like being on a very fast carousel that you can't get off. It brings feelings of panic, fear and vulnerability.

Alongside of this, a health professional adjusted my bed without telling me, and I responded with loud protest and cries of pain. I was subsequently described as showing typical aggressive behaviour of dementia. In my mind, I was reacting to unexpected pain in a very normal way. The word 'aggressive' was so humiliating both for me and my daughter who was also present, as this did not in any way reflect the person that I was, and still am. This was a 'reflex' response to pain, mistakenly labelled as aggression.

After I was discharged, the pain continued, of course. My family noticed that I was pacing around and walking a lot. They wondered if the fall had exacerbated the dementia and if I had begun 'wandering'. However, when they took the trouble to ask deeper questions and actually interpret my responses, it turned out that I was trying to 'walk away' from the pain or 'leave it behind'. This is another example of how my brain will try to take reasonable action to pain, which is easily labelled as wandering.

In explaining my experience, it is my hope that you will get a glimpse of how the language in the BRUA is misleading, derogatory, and certainly does not in any way reflect the resources that may be required to support someone living with changed and responsive behaviour.

When one reads the BRUA within a human rights context, the language is shaming and derogatory, particularly in the context of mental illness and dementia. The overall tone and wording of the tool very directly implies nefarious intent on behalf of the participant. For example, terms such as 'manipulative' and 'attention seeking' are simply impossible in the context of dementia.

When it is understood that when the disease takes the mind body connection away, that the body will continue to respond to the pure anguish, pain and grief of living in a world you no longer understand in any way it can. There are few positive emotions associated with vulnerability, and to my mind, it is wholly reasonable that a human being who has led a full and useful life will be in desperate emotional pain as they lose connection to that life. It is further reasonable that if communication skills are impaired or gone, that the physical body will attempt to express this pain in any way it can.

I would also draw your attention to the impact of this language on assessors, care staff and families who read and use the tool and associated reports. Surely this language will have an impact, at the very least, depersonalising and demonising the individual, and perpetuating fundamental misunderstanding of what funding may be required to support people with these symptoms.

It is also unclear to me, why it is seen to be acceptable to use a tool designed for school leavers with a disability looking for work, on older vulnerable Australians, often living with dementia and mental health difficulties.

While I do understand the rationale of expediency given in the report, and the reassurances of the Department for Health and Ageing that the BRUA represents a very small part of the overall AN-ACC assessment, surely our older people deserve a better understanding when being assessed for funding requirements.

While I also appreciate that statistically the tool may give similar outcomes to more appropriate and sophisticated models, the point is that perpetuating blame, shame and stigma is in nobody's interest, and I am very surprised that the Australian Department of Health felt this tool to fit within the foundational principles of Age Care reform in respect of human rights.

The overall AN-ACC model is capacity based; however, this model has been reversed with the inclusion of the BRUA, which is backward looking. This change of approach appears inconsistent at best, harmful at worst.

The relationship between difficult behaviours and the resources required to properly support people who are experiencing these symptoms is unclear. The Department of Health have advised me that assessors will be trained to interpret the wording in the tool into appropriate language, and that the assessment results will not be shared outside of the funding circle.

In practice, Age care facilities are embedding the AD-ACC into their operational systems in order to anticipate funding, thus further perpetuating the fundamental misunderstanding of changed behaviour. While this may limit the potential scope of the unacceptable and discriminatory words, they still exist in the world, and the fact that they are in circulation in a government approved tool is simply shameful.

I am surprised and disappointed in the lack of leadership shown by our department of health and our government. The community take our cues for best practice from the spoken and unspoken signals of our government, and when the government freely use and share such offensive outdated and discriminatory language in a formal setting, this does not fit within the expectation of a human rights based new and revamped age care system. It's as if the government have parked a Skoda into the Tesla showroom, it doesn't belong. The tool was developed in a different time for a different cohort. It is no longer relevant or acceptable in today's world.

It is also a matter of concern for me that even though changed behavior is a massive fear in Dementia, emergence of such symptoms are not directly linked to the ability to reassess a person. Instead, due to the lack of functionality of the tool, it's hoped that residential care staff will figure out that this change in circumstances is covered in a different section of the tool – the cognitive part. To my mind, the inclusion of the BRUA places a lot of expectation of mental gymnastics to assessors and care staff. Is this efficient or effective?

When I discussed the BRUA within my wider social circle, the responses I received were enlightening. They ranged from WTF, to 'disgraceful, backward, humiliating, inaccurate, outrageous and shameful'.

I also wonder if the BRUA would have been included if the team developing the AN-ACC had included lived experience. There is little doubt that the Mental Health community and the Dementia community would have protested loudly. Is this an example of indirect discrimination, as the stereotype prevails that people living with dementia 'won't remember' or 'don't understand' so it doesn't matter what we call them?

How does such offensive language fit into the future of Age and Dementia Care? How does it fit with the Disability Discrimination Act Section 5. Why is it acceptable to use these terms on people living in residential care with disabilities, and not in the wider community? Is it because we aren't that important?

It is my sincere hope that the BRUA part of the funding tool can be reviewed. Not with a view to fitting into a structure where assessors don't have the training or capacity to make judgements; but with a view to understanding the drivers of such symptoms, appropriate language and the costs of safely supporting the individual experiencing these devastating symptoms without shame, blame or other negative connotations. A trauma informed context when examining the matter of misplaced expression in Dementia may prove enlightening.

We aren't being difficult because we want to be, we don't have the brain power to make a nefarious plan to stuff up your day. This happens because of the anguish and often physical pain we live with that our broken brains have no other way to express.

Warmest Regards, Theresa Flavin